# TESTIMONY OF THE GILA RIVER INDIAN COMMUNITY BEFORE THE SENATE COMMITTEE ON INDIAN AFFAIRS

## REAUTHORIZATION OF THE INDIAN HEALTH CARE IMPROVEMENT ACT

Washington, D.C. March 8, 2000

#### INTRODUCTION

Good morning, Chairman Campbell and Members of the Committee. My name is Richard Narcia and I am the Lieutenant Governor of the Gila River Indian Community. I am honored to have the opportunity to provide my Community's views on the draft bill to reauthorize the Indian Health Care Improvement Act and to give our perspective on the importance of Indian Health Service (IHS) programs to the daily lives of our tribal members and other Native Americans. I am pleased to be accompanied today by Karen White, Chair of our Council's Health and Social Welfare Standing Committee.

Our Community is located in south central Arizona, on the outskirts of Phoenix. We have a young and rapidly growing population that presents us with a variety of health care challenges. The most serious health challenge we face is a tremendously disproportionate rate of Type 2 diabetes in our population, which I will discuss with you in more detail today.

Since Fiscal Year 1996, our Community has provided preventive health and primary care services to our population through Indian Self-Determination contracts with IHS. The IHS program dollars we receive have allowed us to make incredible strides in improving health care by tailoring our services to our specific needs. IHS program dollars are also critical to our goal of moving our Community from the IHS's acute-care model to a prevention and maintenance model better suited to the treatment of diabetes.

## INDIAN HEALTH CARE IMPROVEMENT ACT

I will begin first with a few comments on the draft reauthorization bill. I will then share with the Committee the challenge our Community has been facing from diabetes so that the Committee can better understand the importance of Indian Health Care Improvement Act programs to our health and welfare.

Our Community supports the draft reauthorization bill and, specifically, the following provisions:

We strongly support the wording in the draft bill that would change the Act's national goal of improving Indian health from the "highest possible level" to "at least as good as the Nation as a whole." We feel that measuring Indian health in comparison to the national standard is the fairest way to ensure that the Native American community receives the improvements in health care delivery that we deserve. It is more than breathtaking to us that, in this period of unprecedented national prosperity, Native Americans continue to suffer more and longer, and die decades earlier, than most other Americans due to inadequate health care.

With respect to Title I, Health Professions, as a community providing services under an Indian Self-Determination contract with IHS, we want to ensure our health profession staffing needs are given consideration on an equal basis with programs operated by the IHS. There are several sections in the draft bill that specifically provide this directive and the Community would want to see the IHS implement this directive. Section 123 would also designate all programs operated by tribes as Health Profession Shortage Areas. In the past, our Community's inability to receive this designation inhibited our ability to participate in recruitment and retention initiatives. As a result, we strongly support this provision.

With respect to Title II, Health Services, our Community supports the goals of section 201, which would reinstitute the Indian Health Care Improvement Fund. The fund has been used in the past to try and achieve equality among IHS funded programs. Currently, it is estimated that our Community is funded at only 54% of the amount IHS calculates as the Community's full need. It is our hope that the Indian Health Care Improvement Fund will help address our funding deficit, provided that sufficient funds to meet our need are appropriated.

The Community strongly supports the goals of section 204 that would make the model diabetes programs recurring through the year 2012. Our Community has a model program for registry and data collection, but it has evolved only with the dedication of considerable resources. In fulfilling the goals of section 204, we would urge the Congress and the Administration to devote necessary resources to implement this section in a meaningful way. We also support the revision to Section 204 of Title II that adds authority for funding to establish, equip and staff kidney dialysis programs.

With respect to Title III, Health Facilities, our Community supports new financing options, such as the Health Care Facility Loan Fund. The Community is in need of expanding health facilities in other areas of our reservation and we may want to participate in such an initiative. We support the increased ability of IHS to seek out creative ways to meet unmet health facility needs and foster partnerships to build necessary facilities. Given the nearly quarter-of-a-billion dollar backlog in health facility construction need in Indian Country, it only makes sense that the IHS support creative partnerships to build necessary health care facilities.

We also support new Section 317 of Title III that would give IHS the flexibility of using funding from other sources to address health care facility construction needs.

With respect to Title VI, Organizational Improvements, our Community requiring IHS to develop an Automated Management Information System and to provide all contracting tribes an automated management information system. We believe this is vitally important and urge the

Congress and the Administration to fund the provision at an adequate level. We also strongly support the change to Title VI that would elevate the Director of IHS to Assistant Secretary level.

Our Community also supports the intent of Section 813, which would provide authority to tribes and tribal organizations to act as ordering agents under the IHS Prime Vendor contract. In our Community, we have seen our drug costs double since 1995 to approximately \$1.6 million annually. From 1998-1999, the total increase in cost for our top 11 drugs was approximately \$413,000. In the coming year, we expect the overall cost to increase another 8%. Expanding the authority for tribes to participate in the Prime Vendor Contract will allow some savings in drug costs and, importantly, the administrative costs that currently exist in the IHS system.

As a final matter, the Community supports the establishment of an INMED Program in the Southwest. Section 114 of the Indian Health Care Improvement Act currently provides that at least three grants may be provided to colleges and universities. The Community supports IHS providing a grant to the University of Arizona for the establishment of an INMED program in the Southwest. Currently, there are INMED Programs in Minnesota, North Dakota, and Montana.

Overall, the Community supports the goals of the draft bill that seek to strengthen the delivery of health care in Indian Country. As it is well known, the availability of adequate resources is a primary concern. We are hopeful that as the Committee further develops the draft bill, there will be consideration given to funding issues. We believe our Community can serve as a model for health care delivery in Indian Country and as the Congress seeks to create a Bipartisan Commission on Indian Health Care Entitlement, we would ask that you consider our Community's participation on such a commission.

#### THE DIABETES CHALLENGE

I would like to turn next to the topic of diabetes. I believe that our Community's experience with diabetes illustrates clearly the importance of IHS programs to the every day health and well-being of Native Americans.

According to IHS, diabetes was the most frequently identified health problem cited during the IHS Area budget formulation workshops for FY 2001. According to IHS, Native Americans are almost three times more likely to have diabetes than the general population and are four times more likely to die from it. The mortality rate, according to IHS, is clearly on the rise. In a troubling development, the prevalence of diabetes has risen as much as 36% among Native American children and adolescents.

## GILA RIVER INDIAN COMMUNITY'S EXPERIENCE WITH DIABETES

Our Community has the unfortunate distinction of being well-known in the medical world for its shockingly high rate of Type 2 (adult-onset) diabetes. In fact, the Pima Indians that make up our Community have the highest known rate of diabetes in the world, according to the World Health Organization. Eighty percent of Pimas over age 55 have diabetes and Pimas are 12 times more likely than the general population to die of diabetes. In our Community alone, over thirty percent of adults over age 35 have diabetes. Until recently, our children were not affected by the

disease until they reached adulthood. Unfortunately, that is no longer true. Our children are being diagnosed with diabetes with increasing frequency. Today, there are 50 Gila River children with diabetes, the largest cluster of children with Type 2 in the world.

The disease and its devastating complications, including kidney disease, limb damage, amputations, and blindness, pose a serious and costly health care challenge to our Community and, indeed, the world. The World Health Organization estimates that by 2025, 300 million people will have Type 2 diabetes.

As a result of our extraordinarily high rate of diabetes, members of our Community have been studied extensively by the National Institute of Health (NIH). The NIH National Institute for Diabetes and Digestive and Kidney Diseases (NIDDK) has supported a field research station in Arizona since 1965 to study the Pima Indians for causes of diabetes. Our local paper, the *Arizona Republic*, recently ran a series on the diabetes problem within our Community and the NIH research effort, entitled "A People in Peril: Pimas on the Front Lines of an Epidemic." We have included that series of articles in the hearing record as an attachment to our testimony.

As stated by the *Arizona Republic*, "the Pima are the most studied people on the planet. They've been weighed, poked, prodded, X-rayed and screened at a cost to taxpayers of more than \$100 million." Nearly 80 percent of our Community, 9,000 people, took part in the research. Based on the data obtained, NIH was able to develop new approaches to the treatment of Type 1 diabetes, juvenile diabetes. The study also identified unhealthy weight and genetics as strong risk factors for Type 1 diabetes and isolated the role of high blood pressure in predicting complications of diabetes, including eye and kidney disease.

Notwithstanding the knowledge gained by the NIH research involving Pimas, after 35 years the rate of diabetes in our population continues to skyrocket out of control. Unfortunately, the NIH research program findings failed to study the treatment and prevention of Type 2 diabetes, the type of diabetes that affects the very people that were used to obtain the precious data.

According to the *Arizona Republic* article, NIH had several opportunities available in the past twenty years to fund research and prevention efforts for Type 2 diabetes programs in our Community, but they chose instead to spend over \$150 million to research Type 1 diabetes, which is not prevalent in Native American communities. It took 15 years for NIH to turn some of its cross-over research findings into a formal program on diabetes education among Pimas, after the Tribal Chronic Illness Project was launched in 1980. That program consisted of only one visiting nurse, who left in 1986 to attend medical school. Not until 1996, 31 years after identifying the Type 2 diabetes problem in our Community, did NIH launch a nationwide Type 2 diabetes prevention study including Pima volunteers.

According to the *Arizona Republic*, Dr. Barbara Broussard, Director of the IHS diabetes programs in 1996 and 1997, said that the NIH missed a critical prevention opportunity. She is quoted as saying, "There were small fledgling efforts [by NIH], but it was not enough for the scale of the problem. It was sort of like taking a water hose out there for a forest fire."

We relate this experience not to gain the sympathy of the Committee, but to describe to you what it has taught us. The most important lesson we have learned from this experience is that tribal self-interest requires that tribes have direct control over intervention in, and treatment of, serious diseases affecting their population in numbers disproportionate to the rest of the population, such as Type 2 diabetes. The Indian Health Care Improvement Act and the programs authorized therein have been, and continue to be, our critical conduit to obtaining that control.

## THE NEED FOR INCREASED FUNDS TARGETED TOWARD DIABETES

As stated, the Indian Health Care Improvement Act authorizes the health care delivery programs through which tribes receive self-determination contract funds to target the health services most needed by their populations. Since taking over provision of health care services through a Self-Determination contract with IHS, our Community has a higher level of health care than was ever possible through direct IHS service because of our ability to target uses of the program dollars. Clearly, however, we have a long way to go in order to beat diabetes in our Community.

We note that the President's Fiscal Year 2001 budget includes a \$3.88 million increase for diabetes programs in the IHS budget. In addition, the IHS budget request includes an annual transfer appropriation of \$30 million pursuant to the Balanced Budget Act of 1997 for the Special Diabetes Program for Indians (SDPI). SDPI provides grants to IHS and tribes for the prevention and treatment of diabetes. The SDPI funds have been used as seed money to start over three hundred new tribal diabetes programs. According to IHS, many of these programs, a majority of which are tribally run, are creating innovative, culturally-appropriate strategies to address diabetes.

What tribes are discovering, however, is that they are just beginning to scratch the surface of the diabetes problem in Indian Country. Tribes are reporting to IHS the need for additional trained personnel, support, technical assistance and continued funding beyond the five-year SDPI program term. According to IHS, tribes are just beginning to exert a growing influence in the management of diabetes programs as the number of tribally managed diabetes programs continues to grow steadily. Clearly, IHS must continue to support the initiation and expansion of tribally-run diabetes treatment and prevention programs.

# GILA RIVER PLANS FOR INTERVENTION CENTER

Our Community has not been passive in its fight against the deadly disease of diabetes. As one member of our community recently stated, "The story of diabetes on the Gila River Indian Community is about more than alarming statistics and tragic numbers. It's about families and individuals living with and working through a disease that has become a worldwide public health issue." Our Community has escalated its diabetes treatment and prevention efforts since taking control of our health care delivery in 1996 pursuant to an Indian Self-Determination contract with IHS. Our Community already has in place health care services that equal or surpass many other health care delivery systems in the country. We are ready to move to the next level.

The Community has long been frustrated by the lack of successful intervention in our Community to stem the progression of diabetes and its severe complications. As a result, the Community is currently exploring the possibility of establishing a Center on Community land to address the diabetes epidemic raging in our population.

The purpose of the Center would be to develop new diabetes intervention techniques specific to our Community and to train professionals in such techniques. The Center would transfer all control over intervention and treatment to the Community and coordinate with research activity being undertaken by the Community and outside agencies, including NIH.

## **CONCLUSION**

We want to take this opportunity to thank Chairman Campbell and other distinguished Senators on the Committee for their demonstrated concern about the high rate of diabetes in the Native American community. We look forward to continuing to work with the Committee in our effort to win the war against diabetes and other serious health challenges that affect our Native American communities in disproportionate numbers.

We thank the Committee for inviting us to submit our views on the draft reauthorization legislation and to share the importance of IHS health programs to our Community.

I would be happy to answer any questions the Committee may have at this time.